

DESIGN FOR SIBLINGS OF CHILDREN IN NEED OF INTENSIVE CARE

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ABSTRACT

Having a sibling with an illness or disability can be very stressful. Siblings in this context need sufficient support, otherwise this can have a negative impact on the long-term well-being of the siblings. Today we see all too often that these siblings are a kind of forgotten group. Parents are often very busy caring for their sick or disabled child and siblings often fade into the background. As a result, siblings often push themselves to the side and have difficulty expressing their emotions because they do not want to be a burden to their parents. Therefore, the right support is needed to promote siblings' mental well-being, self-expression, and skills. Despite the various studies already conducted, the current support system is still often inadequate. There is a lack of recognition of organizations that support siblings in this context, even though there is a substantial need for them. Funding and recognition are still often a problem today. In this paper, the needs and problems of siblings are examined through qualitative research. Based on the collected insights, a list of requirements was composed that can help designers to support siblings in expressing their feelings and stimulate communication between parents and child. This paper contributes to the literature on the well-being of siblings of children with illnesses or disabilities, by looking at the problem from a different angle. In this way, an attempt is made to prevent mental problems in the long run and to offer adequate support.

Keywords: Sibling support, well-being of siblings, disability, childhood illness, product service system

1 INTRODUCTION

About 82% of all children grow up with a brother or sister [1]. The sibling relationship is therefore important and has a great influence on the child's development. It is the longest lasting relationship in the life of an individual, as it starts at birth and continues throughout life [2]. The brother-sister relationship in most cases lasts longer than the parent-child relationship, as parents usually die sooner than their children [2]. What does this relationship look like for siblings of children who need intensive care, what are the differences and similarities with an ordinary brother-sister relationship, what difficulties do these siblings experience and what can we do to support them sufficiently? This paper examines the sibling relationship and the different needs and difficulties that siblings of children with a disability or illness face. By means of qualitative research in the form of a literature study, in-depth interviews and short questionnaires, information concerning the theme is mapped out and analysed.

2 PROBLEM DEFINITION

The brother-sister relationship is dynamic. As you grow older, you will experience the relationship differently. So, it changes over the years [3]. Having a brother or sister with a disability or a serious illness can cause a lot of stress and tension that can lead to problems and overburdening later in life. Yet here too, the bond is unique and unbreakable [3]. Siblings of children who need intensive care sometimes experience conflicting and unresolved feelings and it is not always easy to deal with this. On top of this, they are three times more likely to experience mental problems and overburdening [4]. It is therefore important that they receive sufficient support to prevent the negative long-term effects. Today, it still appears all too often that these siblings are a forgotten group. In families where one of the children has a serious illness or disability, all the attention of the parents and caregivers often goes to the sick or disabled child. This is very normal and logical. However, it should be considered that this can also influence the development of the other siblings. It is not easy for parents to find extra time for their other children, so they often fade into the background and teach themselves not to talk about conflicting feelings such as anger, frustration, fear, jealousy, or guilt, because they do not want to burden their

parents with them. Even though they usually have a great deal of understanding for the situation, they may also experience it as unfair because they receive less attention. Siblings of children who need intensive care often feel that they have extra responsibility and take over tasks from their parents or help to take care of the sick child or child with a disability [5]. They worry about their sick brother or sister. Open communication about the illness or disability is therefore important to avoid fear, incomprehension, guilt and wrong thinking or expectations on the part of the siblings [5].

These siblings need the right attention, sufficient support, and the necessary understanding for the various feelings they experience throughout their lives. In this way, mental problems and overburdening later in life can be prevented. Communication between parent and child is essential. Today, there are few or no tools that focus on the communication between parent and child, and therefore few tools available that can be used at home without the help or presence of a caregiver. Here lies a great opportunity for designers.

3 CURRENT STATE OF THE ART

Over the past 40 years, there has been increasing interest in siblings of children who need intensive care. This is logical since inclusion is becoming more and more important in our society [6]. Various studies have been conducted to examine the influence of having a sibling with a disability or illness. These studies have often produced contradictory results. For example, many studies indicate that having a sibling with a disability or illness has a negative impact on the development of the sibling, while other studies indicate that it has a positive impact on development. Moyson's [3] research shows that these contradictions can be explained by the fact that the sibling's relationship is always a unique and dynamic one, but also by the fact that most research is done with adult siblings. Using adult siblings ensures that often the memories that have stayed with them are the ones who are told the most. These will be the most negative and most positive memories, which can lead to contradictions in existing studies. The sibling's relationship is unique and special, and each sibling reacts differently to his or her situation. This is confirmed by the contradictory results of the studies. Moyson [3] noted that no universally valid conclusions can be formulated about this relationship.

3.1 Context

Children with an illness or disability require a lot of attention and care. This care can be provided by the parents and siblings, but sometimes a caregiver is called in when the care becomes too heavy. Also, for the siblings themselves, a counsellor can be called in to find out how they feel about the situation. Siblings can often also turn to certain teachers, friends, or family at school. Having a sibling with a disability influences the lives of these siblings. The impact depends on various factors within the family, in the network surrounding the family and in society [7]. Every sibling is in a different situation and will need support in a different way or in a different place. Some siblings spend a lot of time in the hospital because their brother or sister must go there often, while others hardly ever come into contact with the hospital. The place where these siblings need support depends on their specific situation. Why do they need support? These siblings often must deal with the concept of "living loss". When having a sibling with a disability, it can sometimes feel like a "living loss". It can be difficult for a sibling to cope with important moments in their life such as marriage, childbirth, and graduation. This because they are constantly reminded that their brother or sister may never be able to experience this themselves. In addition, having a brother or sister with a disability or serious illness can sometimes feel unfair since their sibling who needs intensive care is entitled to more attention, care, or support [3]. These siblings may feel that they always must be the ones who 'give' and that they never get anything in return [4]. It is therefore important that not only parents, but also caregivers give them sufficient attention and support so that they know they are also important and that they are also thought of.

Today, there are several organisations dedicated to the well-being of siblings of children who need intensive care. Most of these organisations organise sibling days to put siblings in the spotlight. During such a sibling day, fun activities are organised, such as going to the zoo, or a handicraft workshop... This way, siblings can meet each other. Many organisations also aim to expand the knowledge and skills of these siblings. For example, courses are organised in which siblings learn how to deal with their brother or sister with autism, or days are organised in which siblings can visit an operating theatre because their brother or sister often must be there. There are also organisations, such as Kadodder, who offer home counselling for siblings. This counselling often consists of a simple conversation with the sibling. This way they feel they matter and that they are not alone. Counsellors can then give tips to parents on how to deal with the situation.

4 RESEARCH METHODS

As a research strategy, qualitative research was chosen in the form of literature study and in-depth interviews. Various sources were consulted, such as the ‘Brothers and Sisters Book’ by van Dijken [4], but also various papers. In addition, in-depth interviews were conducted with the main stakeholders. In this way, the needs, and underlying thoughts of siblings of children who need intensive care could be mapped out further.

5 FINDINGS & DISCUSSION

5.1 Literature exploration

The image of siblings of children who need intensive care has evolved a lot over the years. From the literature exploration it is clear that in the past, the focus was very much on the negative effects of being a sibling of someone who needs intensive care. However, the study by Poppe et al [6] shows that in recent years a more nuanced and positive view has emerged about being one of these siblings.

But it is not always easy. Siblings of children who need intensive care often have different experiences from their peers, which can make it difficult for them to connect with their peers. Various studies have repeatedly shown that in families where a chronically ill or disabled child is present, the attention of parents, but also of care providers, is mainly focused on the ill or disabled child [9]. In families where there are other children present, this can cause these children to end up in a difficult position [4]. Various studies also point to the fact that these siblings are more likely to cause mental problems and overburdening. This overburdening may be caused by the excessive expectations set by parents. Often, parents do not realise that they are setting other expectations for the siblings and that these expectations are sometimes too high.

As mentioned earlier, it is important to realise that the sibling’s relationship is a unique and complex one and that it is not easy, or even possible, to define this relationship in a one-sided and straightforward way [6]. Siblings describe being a sibling of someone who needs intensive care as a “dynamic continuum with positive effects at one end and negative effects at the other” [6]. How they feel and where they are on this continuum depends on the situation, they are in. It is also important to bear in mind that not every sibling has the same needs, it depends very much on their home situation and the relationship they have with their parents.

According to the research of Moyson [7], there are nine domains that influence the well-being of these siblings, namely: joint activities, mutual understanding, own time, acceptance, tolerance of behaviour, concern for sibling welfare, sharing of experiences, support from the environment, dealing with the outside world. Moyson [7] indicates that siblings who do activities together with their brother or sister with a disability or illness, and experience these activities as something positive, but are also able to do things on their own, usually accept being a sibling of someone who needs intensive care. When joint activities do not go well or there is no balance between the two, being a sibling of someone who needs intensive care is more likely to be perceived as an inconvenience and acceptance will be more difficult or even non-existent. Of course, the acceptance process also depends on other factors [7]. Another striking fact from her research [7] is that almost all the siblings indicated that meeting fellow sufferers has a positive effect on their well-being. This is also reflected in the nine domains. These domains can be used by parents or caregivers to start conversations with the siblings and to find out how they are feeling. Designers could implement these nine domains in products or services that can support siblings in this situation.

In addition to the negative consequences of being a sibling, it is also important to consider the positive consequences. For example, these siblings often have a higher degree of maturity, compassion, and resilience. They are less likely to have prejudices about someone because of their own situation and experiences. This was also mentioned in the in-depth interviews that were done. As a parent or caregiver, it is important to capitalise on these success stories. Ask what activities they enjoy doing together, or what they have learned from their sick or disabled sibling. It is important not to focus only on the negative aspects of being a sibling of someone who needs intensive care. When siblings are actively asked about the positive effects, they are more likely to consider them [7].

5.2 Interviews

A total of ten people were interviewed for the study, including four adult siblings, one parent, one paediatric oncology trainee, three experts and one expert who also is a sibling of someone who needs intensive care. For each interview a structured questionnaire was drawn up which served as a guideline

for the discussion. The questionnaire was not strictly followed. From these interviews, several insights emerged that confirmed and complemented the findings from the literature studies.

5.2.1 Siblings

Earlier in this paper it was mentioned that siblings of children who need intensive care are up to three times more likely to have mental problems. This was also evident from the interviews, where three out of five siblings of children who need intensive care indicated that they ever needed psychological help because they were struggling. One of the siblings also said that she did not need it herself, but her brother did. Two of the five siblings even indicated that they themselves fell into a depression and several siblings indicated that their parents had different expectations of them and that they felt this was not fair and sometimes difficult. According to these siblings it is difficult to see their brother or sister being treated differently and being allowed more than them. They also indicated that they sometimes felt held back in their development because they could not always be 100% the brother or sister they wanted to be and sometimes put themselves aside in order not to burden their parents. Talking about it is very personal and makes you vulnerable. "By talking about it I felt relieved but also misunderstood because my dad said: it is not that bad after all" (J. VM, personal communication, 22 November 2021).

There is a difference between siblings of children with a congenital disease and siblings of children with a non-congenital disease. The first ones get more used to it because they grow up with it. Most of them accept it as part of their normality (A. B, personal communication, 29 October 2021). However, it is important to realise that it can still be difficult for them. Just because something is normal does not mean it is necessarily easy (A. M, personal communication, 25 October 2021). For siblings of children with a non-congenital illness it is a little different. They often must learn to cope with sudden changes. Many fun activities are suddenly not available to them, and their family situation suddenly changes (A. B, personal communication, 29 October 2021). In addition, there is also a difference in how siblings express their emotions. Some of them internalise their emotions very strongly, some of them externalise them very strongly and some of them do both (A. M, personal communication, 25 November 2021). Siblings who internalise their emotions and thus often hide them are often seen as the 'perfect sibling' because parents often do not notice that they are struggling. These siblings will often do well at school, help out at home and try to excel at everything so that their parents don't have to worry about them. "Yet it is important to realise that these siblings could often crash at any moment" (A. M, personal communication, 25 November 2021).

Siblings who externalise their emotions often become too absorbed in their emotions and express them very strongly. These children are often labelled by parents as the 'annoying or difficult child' because they often display behavioural difficulties (A. M, personal communication, 25 November 2021). However, the origin of this behaviour must also be considered with these children; perhaps they find it difficult to accept that their brother or sister is receiving more attention.

In addition to the negative effects, the positive effects were also mentioned during the interviews. All the siblings indicated that they felt they were less likely to be prejudiced against someone because of their own situation, and that they had a higher degree of maturity and independence.

5.2.2 Parents

Parents can also find it difficult to accept that their child needs intensive care. The interviews showed that parents often wonder whether they have done something wrong, and whether it is their fault that their child has a disability or illness. The situation not only changes the lives of the siblings, but also the lives of the parents. They are usually aware that they give less attention to their other children, but often feel that they simply do not have enough time to give both children enough attention. The relationship between parents is also very much put to the test by having a child with a disability or illness. Not all relationships are strong enough to deal with this. The interviews also indicated that parents often do not know that there is something wrong with their other child because they are often so focused on the sick or disabled child. Therefore, it would be helpful for parents if siblings could express how they feel in a clear way.

5.2.3 Experts

Experts indicate that many siblings often seek help too late, when they are already depressed. The initiative to seek help usually has to come from the sibling's environment. In the case of siblings of children with cancer, it often happens that after the treatment or when their brother or sister has been declared cured, they fall into a black hole because they no longer must look after someone. They suddenly have to take control of their own lives again and put themselves first, which is very difficult

(A. B, personal communication, 29 October 2021). Siblings of chronic patients are especially in need of help when things get too much for them. This usually happens when they reach puberty and have to start looking for themselves. It is important for caregivers or parents to make it clear from the start that they are not alone, and that they can go to a care provider if they need it. Open communication towards the sibling is very important, but for parents it is often difficult. Some of them de problematize the disability or illness, while others problematise the situation and make it worse than it is (M. P, personal communication, 25 November 2021). It is very important for siblings to understand why their brother or sister needs more attention.

It is very important that there is sufficient support for siblings to prevent problems later in life. Because it is a difficult topic to talk about, it is important that it can be approached in a light-hearted way so that it is not too heavy (M. P, personal communication, 25 November 2021). This is still something that we miss at the moment” (A. M, personal communication, 25 November 2021). Children must learn from an early age that it is okay to feel how they feel and to express themselves.

6 CONCLUSIONS

It can be concluded that having a brother or sister with a disability or illness has a huge impact on the life of the sibling. Daring to ask for help appears to be one of the greatest difficulties for these siblings because they often don't want to burden their parents, therefore it is important to explicitly indicate to siblings that help is available for them so that they do not have to ask for it themselves. Each sibling lives in his own unique situation and each sibling reacts differently to the situation they find themselves in. However, it can be concluded that despite these unique situations, their needs are often similar. The main corresponding needs are as follows: correct and sufficient information, acknowledgement, adequate attention, meeting other siblings, to be heard and dealing with it lightly.

Designers could have a great impact for these siblings. There is a great opportunity in designing products that can support siblings of children who need intensive care in expressing their feelings and emotions. Through the use of these products, children can learn at an early age that it is okay to feel how they feel and to express their emotions. The use of these products can reduce mental problems and overload in the long term. As for the limitations of this study, conclusions are drawn from a small population. To be more representative, more siblings as well as experts should be interviewed. The siblings that were interviewed were also adults, this is also something important to keep in mind.

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